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Opening Statement of
Chairman Tom A. Coburn, M.D.
Chairman

Subcommittee on Federal Financial Management, Government Information, and
International Security

Addressing Disparities in Federal HIV/AIDS CARE Programs

Today's hearing will examine the financial status of the Ryan White CARE Act, the nation's largest provider of AIDS-specific services, which Congress is expected to reauthorize later this year. I had the privilege of authoring the 2000 reauthorization of this important law and, as a practicing physician, I have cared for numerous patients with HIV who relied upon the CARE Act for their medical needs.

Twenty years ago, I delivered a baby girl who would become the first child I delivered to die from AIDS. I discovered she was infected with HIV after I diagnosed her mother with full-blown AIDS. The mother died two and a half weeks after we learned she had the disease. Her daughter struggled through seven years of treatment before she joined her mother.

Back then, much was still not known about HIV and AIDS. Few medical therapies were available to treat the disease. The epidemic was believed to be almost entirely centered in a few metropolitan areas and among very specific high risk groups. Even within the public health community, fear and lack of knowledge about this new disease left many of those living with the virus unable to access what care that did exist and fear of stigmatization kept many others from even seeking testing or treatment.

Today, HIV affects every state in our Nation and the virus does not discriminate against any particular race, gender, age or sexual behavior. Medical breakthroughs, however, have dramatically transformed HIV infection for many into a chronic, manageable disease and, thereby, have delayed the onset of AIDS. And in 1990, Congress passed the Ryan White CARE Act to provide for the unmet health needs of persons living with HIV disease. The CARE Act was named after Ryan White, an Indiana teenager whose courageous struggle with HIV/AIDS and against AIDS-related discrimination helped educate the nation.

While the face of AIDS has changed, our federal response has been slow to adapt to those changes.

Funding for the CARE Act has increased dramatically from \$257 million in 1991 to over \$2 billion in 2005, yet thousands of Americans with HIV are on waiting lists for access for life saving AIDS medications and many others face formulary restrictions.

And while patients in Kentucky and West Virginia have died while on waiting lists for treatment provided by the AIDS Drug Assistance Program (ADAP), one metropolitan area is actually receiving CARE Act funds for the deceased. Furthermore, tens of millions of CARE Act dollars go unspent annually in some jurisdictions while other states find themselves faced with cutting patients' access to AIDS drugs.

These disparities have been created by a number of factors.

First, the CARE Act continues to distribute federal funds based not upon the number of people with HIV but rather AIDS, the end stage of HIV infection. It often takes up to ten years for AIDS to develop after HIV infection. Because AIDS cases comprise only a fraction of the total population of those living with HIV, this misplaced emphasis as a basis for CARE Act funding ignores the vast majority of those with HIV. These affected communities are being ignored and not receiving their fair share of federal support. Studies have shown those with HIV but not AIDS are much more likely to be women, African Americans, Hispanics, and those who live in rural areas. Incorporating HIV data into funding formulas and prevention strategies will ensure we stay in front of the disease and that resources are directed to where the disease is headed rather than where it was a decade ago.

In 2000, Congress sought to eliminate these disparities and treat all people with HIV/AIDS equally under the CARE Act by incorporating all those living with HIV, rather than just those diagnosed with AIDS, in funding formulas. The law requires that beginning no later than Fiscal Year 2007, cases of HIV disease reported to and confirmed by the Director of the Centers for Disease Control and Prevention as sufficiently accurate and reliable will be the basis of CARE Act funding formulas.

Funding disparities have also been created by a "hold harmless" provision in Title I of the CARE Act. This hold harmless was intended to ensure that no eligible metropolitan area (EMA) suffered from dramatic funding decreases from one year to the next.

While well intentioned, this hold harmless has ironically caused harm to many areas and all but one of the 51 EMAs would fare better if the hold harmless was eliminated altogether.

Last year, the San Francisco EMA received 92 percent of the hold harmless funding. As a result, San Francisco receives twice the amount per AIDS case as every other EMA and actually receives funding for AIDS patients that have long since passed away. The city finds itself in a unique position where it must find ways to spend excess money on nonessential services while its reported AIDS cases continue to drop. In sharp contrast, the largest AIDS service provider in the Washington, DC EMA is faced with dire financial problems that have forced the closing of several offices and massive staff layoffs, despite a growing population affected by HIV/AIDS.

In addition, some states benefit from “double counting,” in which AIDS cases are actually counted twice, once for funding under Title I and again under Title II. States that receive Title I funding receive 38 percent more per AIDS case than states without an EMA.

Beyond simply addressing the formulas to ensure funding equity, services provided by the CARE Act must also be updated. When it became law 15 years ago, few medical therapies existed and the CARE Act primarily provided social services and end of life care for those with HIV/AIDS. Since that time, medical breakthroughs have contributed to a great transformation in the lives of those with HIV. AIDS deaths have dropped significantly and for many, HIV has become a chronic rather than a terminal disease. As a result, more Americans are living with HIV than ever before and the cost of life saving drugs is considerable. A drug combination including Fuzeon, for example, can cost between \$30,000 and \$35,000 a year to treat a single patient.

This incredible cost to provide essential treatment underscores the need to prioritize core medical services and effective prevention.

The U.S. federal government is expected to spend nearly \$20 billion on HIV/AIDS related programs this year alone and we as a nation have committed ourselves to providing billions of dollars worth of medication and care services to those living with HIV in Africa and elsewhere. Clearly, there is no acceptable reason why with such a large financial investment that any American living with HIV can not access medically necessary care.

I look forward to hearing from our witnesses today who include: Dr. Marcia Crosse, Director of the Government Accountability Office’s Public Health and Military Health Care Issues; Dr. Deborah Hopson, Associate Administrator of the Health Resources and Services Administration’s HIV/AIDS bureau; Dr. Robert Janssen, Director of the Divisions of HIV/AIDS Prevention of the National Center for HIV, STD, and TB Prevention at the Centers for Disease Control and Prevention; and Dr. Michael Montgomery, Chief of the Office of AIDS for the California Department of Health Services.